Subcommittee on Science Technology and Space
of the Senate Committee on Commerce, Science, and Transportation

Hearing on E-Health and Technology: Empowering Consumers
in a Simpler, More Cost-Effective Health Care System
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Good afternoon. I want to thank Chairman Wyden, Ranking Member Allen, and the members of the Subcommittee for the opportunity to be here today. Improving the quality and cost-effectiveness of health care for our Nation's 270 million citizens is one of the great challenges of our time, so I am pleased to be able to join in this discussion.

Background

First, a little background. I am here as a representative of the President's Information Technology Advisory Committee, or PITAC, and the co-chair of PITAC's Panel on Transforming Health Care. I believe you each have copies of the report we issued in February of this year.

PITAC is a group of 24 information technology leaders in industry and academe. Our charge is to provide independent guidance to the President on maintaining U.S. leadership in high performance computing, networking, and information technology research and development. In February 1999, PITAC issued a major report on the status of information technology R&D. (That is the maroon document that we have provided to you).

In that report, we described 10 major areas of our national life – including health care – in which information technology could have a transforming effect that will benefit all Americans. As a follow up to that report, PITAC established a number of Panels to conduct more targeted analyses of the information technology barriers and opportunities in specific challenge areas.

My co-chair on the health care panel was Dr. Ted Shortliffe, professor and chair of the Department of Medical Informatics at the College of Physicians and Surgeons, Columbia University. He has been particularly interested in the

Federal role in health care information technology for several years, and we have provided you with his recent paper from *Health Affairs* in which he details some pertinent history while identifying problems and some potential solutions.

Our Panel reviewed the current literature and consulted widely with Federal and private-sector experts for a year in developing the targeted findings and recommendations of our report, "Transforming Health Care Through Information Technology."

The Report

Because the focus of this hearing is how information technology can empower health care consumers, I want to read you part of our Panel's patient- and consumer-centric vision of better health care as it could be enabled by information technology in the future:

"Telemedicine applications are commonplace. Specialists use videoconferencing and telesensing methods to interview and even to examine patients who may be hundreds of miles away. … Patients are empowered in making decisions about their own care through new models of interaction with their physicians and ever-increasing access to biomedical information via digital medical libraries and the Internet. New communications and monitoring technologies support treatment of patients comfortably from their own homes."

What then must be done to harness the enormous potential of information technology to empower health care consumers and to maximize the effectiveness of providers and services?

First, our Panel concluded that we have a long way to go: Critical long-term research, technology, and policy issues stand between us and the consumer-centric health care that PITAC describes.

As a Nation, we simply do not yet have a broadly disseminated and accepted national vision of how information technology can enable improved care and more cost-effective systems. Given the fragmented nature of our health care system, it is perhaps not surprising that provider organizations and others in the health industry have not yet come together with a coordinated and shared model of what is required.

More surprising, however, is the lack of Federal leadership in bringing the community together -- convening, guiding, educating, demonstrating, and assuring

an understanding of the strategic role that information technology can play in support of health promotion and health care delivery. Currently, information technology is applied on a piecemeal basis in public health, medical research, and delivery of health care services.

We have sufficient evidence, for example, that computer-based patient records can substantially improve patient care, outcomes, and costs. But many provider organizations lack information about the efficiency of IT solutions in terms of both cost and quality, so it is difficult for them to make appropriate decisions about IT investments.

And there is a real problem of incentives in this regard. We do not have a reimbursement strategy in place to encourage greater investment by health care organizations in advanced technologies. An industry that is already financially stressed has difficulty justifying speculative technology investments in the absence of fiscal incentives and strong supporting data.

In the medical research area, information technology is typically viewed as a tool that researchers may be interested in using for specific disease-focused research. But the result of that researcher-by-researcher approach is redundant efforts and very slow adoption of cutting-edge technologies, plus a failure to recognize that the IT in and of itself is an important and challenging area for biomedical research.

The human genome was decoded this year, not by individual researchers working on desktop computers, but by teams of researchers with access to some of the world's fastest supercomputers capable of storing and rapidly analyzing the vast datasets of genetic information that constituted the genome's biological puzzle. The researchers noted that advanced IT systems accelerated the decoding by as much as a decade.

That's a wonderful research success story that is already producing benefits in better understanding of genetic components in disease processes. But many hard problems remain:

We need much better user interfaces, more reliable software and systems, and more accessible high-quality knowledge repositories for use in patient care. Human life may be at risk if, for example, information sent to medical monitoring or dosage equipment is corrupted or if electronic medical records cannot be accessed in a timely, reliable fashion.

To cite another example: Scientists are generating enormous amounts of raw data

from clinical trials as well as bench research. However, making sense of the raw data in the context of previously published research requires sophisticated information retrieval and management approaches not yet invented. The recent death of a healthy volunteer in an asthma clinical trial, for instance, can be traced to inadequate review of the historical literature regarding documented, fatal reactions to a drug. In spite of the impressive databases from National Library of Medicine, vital information is still not "at our fingertips"

We need to develop integrated decision-support systems that can proactively foster best practices. Such systems will require enhanced information-technology methods and tools that do not exist today.

Just two examples: automated reminders to clinicians and patients regarding follow-up visits and immunizations have been shown to improve health. However, I currently get regular reminders to follow up on my dog's immunizations. I don't on my daughter or myself.

Rapid Alerts to clinicians and patients regarding abnormal lab findings can speed up treatments. However, software that will deliver the power and functionality required for such time-critical communications is lacking in most hospitals today

As a just released Robert Wood Johnson Foundation report points out "eHealth interventions have been shown to enhance social support and cognitive functioning; enhance learning efficiency; improve clinical decision-making and practice; reduce health services utilization; and lower health care costs among certain groups." However, the report goes on to point out that "most assessments of eHealth interventions have been limited to small groups that may not be representative of the parent population, have not been studied through randomized control trials, have had limited follow-up periods or have only assessed proprietary interventions that may or may not be replicable."… "eHealth developers do not routinely conduct evaluations, especially post-market assessment for effectiveness. And when commercial companies and other private sector organizations DO conduct evaluations, the results are often not publicly availableAnd we can't wait for industry to deliver solutions because we don't yet know all of the questions. What we need is a national commitment to do the research it will take to develop an array of 21st century patient-centric applications of information technology.

I should note here that our PITAC health care report points to a significant workforce issue limiting progress toward a more consumer-focused health care system through information technology: Only a tiny group of practitioners and researchers today can operate at the nexus of medicine and IT.

We urgently need to expand the cadre of professionals who have expertise in both fields and who can develop, deploy, and manage the technologies needed by the health care sector.

Recommendations

Over all, our report argues that the Nation must invest in research and development focused on realizing the potential of information technology to support 21st century patient-centered health care, just as we are focusing on the potential of research findings in microbiology to help treat and cure human diseases.

We recommend that the Federal government establish pilot projects, Enabling Technology Centers, and large-scale research programs to study and develop practical uses of information technology in health care systems and biomedical research.

We believe that we cannot get where we need to go within the current patchwork, and piecemeal implementations of technologies, most of which were not designed for the life-and-death issues of patient care or the scale and demands of health information systems.

The Enabling Technology Centers could build on the very good program models of the National Library of Medicine's integrated academic systems and telemedicine grant programs, which have supported the development of applications linking distributed organizations via networks and prototyping technologies for specific health care uses.

These Centers would serve as a resource for developing the dual-trained workforce I mentioned earlier, and would also bring together researchers, clinicians, patients, providers, industry, and government stakeholders to solve health care-specific problems.

With regard to large-scale research projects, the Nation is making significant investments in disease-oriented studies. But there is very little funding to support large scale, long-term studies of information technology interventions with large populations – across disease types.

DHHS's Agency for Healthcare Research Quality and the National Library of Medicine, an integral part of NIH, have funded most of the health IT research to date. And NLM also has built medicine's vital resource databases including

PubMED and genome databases. Their funding is inadequate, however, to meet the depth and breadth of the research issues. For example, some important unanswered questions include:

Use of provider/patient email – Is it clinically effective? Cost effective?? Does it reduce patient visits? Improve patient satisfaction?

Telemedicine for consultations – Studies have repeatedly shown high levels of satisfaction with this approach among rural patients, their primary care providers and specialists. In spite of this apparently positive response, the approach is not yet in general use. Many limiting factors have been identified, including cost of rural connectivity and regulatory issues. However, adequate research funding of studies over longer periods of time could provide answers to solving these problems.

Using the Web to obtain health information – Increasingly, patients (and providers) seek medical information on the Web. But they encounter a bewildering quantity of information of variable quality. We need to study the types of questions patients and clinicians are seeking answers to and where are they looking, and develop strategies for helping them find answers. (A particular problem based on my own work with Native American tribes is that much of the available health information on the Web does not adequately address the needs of minority populations.)

How do we effectively protect patients from the errors that can unavoidably arise when needed information is unavailable to busy clinicians as they struggle to deal with an increasingly complex and time-pressured delivery system? How do we assure that the best information is available at the point of decision making, that warnings are provided when unintended errors are about to occur, and that information can move seamlessly with individuals as they traverse the health system within their own community or, indeed, anywhere in the country? IT offers many solutions to such problems, but solutions not only require organizational commitments and effective demonstrations, but fundamental research in biomedical computing, human cognition, and telecommunications.

Conclusion

PITAC strongly believes that information technologies hold the potential to dramatically improve the U.S. health care system. The barriers are diverse, ranging as they do from basic technology questions that require fundamental research, to human, organizational, and social factors that complicate the application of technology in a complex setting such as health care. But in almost all such areas,

there is a role for the Federal government to play. Our health care report has outlined those roles and we hope that you are your colleagues will find our suggestions engaging and persuasive. The Nation has much to gain if IT is more effectively applied to prevent disease, to reduce errors and expense, and to improve the overall quality of health care for our citizens.

Thank you